

**OPTN Minority Affairs Committee
Meeting Summary
November 8, 2022
Conference Call**

**Paulo Martins, MD, PhD, Chair
Alejandro Diez, MD, Vice Chair**

Introduction

The OPTN Minority Affairs Committee (the Committee) met via Citrix GoToMeeting teleconference on 11/08/2022 to discuss the following agenda items:

1. Review MAC & Kidney Committee Recommendations
2. Discussion & Vote: *Modify Waiting Time for Candidates Affected by race-Inclusive eGFR Calculations*

The following is a summary of the Committee's discussions.

1. Review MAC & Kidney Committee Recommendations

The Committee reviewed the 10/17 Minority Affairs and the 11/7 Kidney Committees recommendations on *Modify Waiting Time for Candidates Affected by race-Inclusive eGFR Calculations*.

Summary of discussion:

Scope

A member commented that the Kidney Committee's recommended eligibility variation, above 20 to 20 or less is more aligned with what the MAC voted on during the in-person committee meeting in Chicago on October 17th. Another member inquired if the above 20 to 20 or less recommendation might make it easier for programs to identify candidates impacted by a race-inclusive eGFR because programs could assess a subset of their list instead of looking through every candidate registered as Black or African American. The presenter explained that the rationale for the above 20 to 20 or less recommendation is to tie late access to the waiting list directly to the use of the race variable in the eGFR calculation. There have been discussions about how the OPTN can help programs assess their waiting list, such as providing and sharing a report with information about candidates who are registered as Black or African American. Programs would still be required to assess their lists and identify the candidates eligible for a wait time modification.

Another member agreed with the scope recommendation and stated that some institutions are still in the interim period of implementing a race-inclusive eGFR equation, therefore having a broader scope may make it easier for institutions to transition to a race-neutral calculation.

Candidate Notification

The Chair agreed that there should be two candidate notifications as it would help increase transparency among the community. Another member stated that if the first notification is sent to all candidates, the second notification should also be sent to all candidates instead of only kidney candidates registered as Black or African American. The presenter replied that the rationale for the second notification only being sent to Black or African American candidates is that these candidates are

the only group of individuals that might be affected. Another member asked if the notifications would include language informing candidates that they would be notified about their eligibility after the program has assessed their waiting list. This member also asked if candidates would have an opportunity to self-advocate. The presenter replied that the notification could include language inviting candidates to bring additional documentation forward to their program for consideration.

The Chair noted that the OPTN would provide a sample notification template for programs to use. They continued, explaining that the notifications need to be in clear, concise language that would be understood by the community and candidates that do not have health literacy.

Another member asked if the first notification would include the criteria for a wait time modification because some candidates may be registered as other regarding race and may not receive the second notification if it is only sent to Black or African American candidates. This member continued regarding the importance of candidates knowing the criteria so they can self-advocate in case, for example, they are listed as a mixed race or identify as Afro-Caribbean, or if a candidate's race was misrepresented during registration. A member clarified that if a candidate is listed as other, they are not adversely affected by a race-inclusive eGFR, as the only potentially affected candidates are those registered as Black or African American.

Another member asked if a candidate is listed as other and can provide documentation about their eGFR, can they gain back waiting time? The Chair replied that race is self-identified, so the candidate should be able to contact their program and ask to have their race changed in the hospital system.

Another member noted that the second notification should notify all candidate that changes have been made for eligible candidates so that candidates who identify as other can ask questions if they feel they were misidentified and may qualify for wait time modifications. A UNOS representative clarified that a candidate is only eligible for the modification if they were registered as Black or African American in the OPTN computer system. If a candidate whose race was misrepresented in the computer system could be affected by a race-inclusive eGFR, then that is outside the scope of this project at this time.

Another member asked if the first notification could state the candidate's race as it is identified in the OPTN computerized system. A UNOS representative replied that the candidate's race information, as it is identified in the OPTN computerized system, could be included in the sample notification.

Should the second notification go to all candidates or candidates listed as Black or African American?

Straw Poll: All candidates- 14, Black/African American candidates only- 1

2. Discussion & Vote: *Modify Waiting Time for Candidates Affected by race-Inclusive eGFR Calculations*

The Committee voted on *Modify Waiting Time for Candidates Affected by race-Inclusive eGFR Calculations*.

Summary of discussion:

Does the Minority Affairs Committee support sending *Modify Waiting Time for Candidates Affected by race-Inclusive eGFR Calculations* as presented today to the OPTN Board of Directors for consideration?

Vote: Support- 15, Abstain- 0, Oppose- 0

Next steps

The Minority Affairs Committee will send *Modify Waiting Time for Candidates Affected by race-Inclusive eGFR Calculations to the Board of Directors* for consideration in December.

Upcoming Meeting

- November 21, 2022

Attendance

- **Committee Members**
 - Paulo Matins
 - Alejandro Diez
 - Nwamaka Eneanya
 - Anthony Panos
 - April Stempien-Otero
 - Ayana Andrews-Joseph
 - Christiana Gjelaj
 - Christine Hwang
 - Jason Narverud
 - Reynold Lopez
 - Stephen Gray
 - Steven Averhart
 - Tatia Jackson
 - Tony Urey
 - Wayne Tsuang
- **HRSA Representatives**
 - Jim Bowman
 - Shelly Grant
- **SRTR Staff**
 - Bryn Thompson
- **UNOS Staff**
 - Tamika Watkins
 - Kelley Poff
 - Lauren Mauk
 - Carol Covington
 - Darby Harris
 - James Alcorn
 - Jesse Howell
 - Kayla Temple
 - Krissy Laurie
 - Lauren Motley
 - Rebecca Murdock
 - Ross Walton
 - Tina Rhoades